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Replacing hospital-based epilepsy clinics with rural epilepsy clinics and education in Uganda: impact on attendance

Christopher Harris[a,b,c], Bwambale George[c], Unity Harris[c], Mary Munyagwa[c] and Anne Greenough[a,b,d]

[a]MRC and Asthma UK Centre in Allergic Mechanisms of Asthma, King's College London, UK; [b]Women and Children's Health, School of Life Course Sciences, Faculty of Life Sciences and Medicine, King's College London, UK; [c]Kagando Hospital, Uganda; [d]NIHR Biomedical Centre at Guy's and St Thomas NHS Foundation Trust and King's College London, UK

CONTACT Anne Greenough ✉ anne.greenough@kcl.ac.uk

Biographical note: Christopher Harris is a Clinical Research Fellow in Neonatology at King's College London; George Bwambale is a Clinical Officer at Kagando Hospital with clinical and administrative responsibility for the epilepsy clinics funded by Accomplish Children's Trust; Unity Harris helped to set up the local clinics in Kagando; Mary Munyagwa is a Paediatric Consultant at Kagando who oversaw the project and is now Medical Director at Kagando Hospital; Anne Greenough is Professor of Neonatology and Clinical Respiratory Physiology at King's College London, Director of Education and Training, King's Health Partners and Vice-President Science and Research at The Royal College of Paediatrics and Child Health.

Contributor statement:
CH and MM designed the audit and interventions. CH, UH, BG and MM collected the data. AG oversaw the analysis of the data and with CH wrote the initial manuscript. All authors were involved in the production of the final manuscript and approved its content.

ABSTRACT

Background: A high proportion of the Ugandan population with epilepsy receive no treatment.

Aim: To determine whether introduction of an agreed multidisciplinary guideline and establishment of a local clinic outside the hospital and four rural satellite clinics improved attendance and follow-up by children with epilepsy in Western Uganda.

Methods: A multidisciplinary team from Kagando Hospital, Kasese, south-west Uganda created a guideline for the management of epilepsy. A clinic local to the hospital and rural satellite clinics were established. Attendance and follow-up were audited for three months before the intervention. Attendance, follow-up and the cost of the hospital, local and rural clinics were audited 6 months and 5 years post intervention.

Results: Pre-intervention, one patient a month attended the free Kagando Hospital epilepsy clinic. Post-intervention, a median of eight patients (range 2–12) attended the local clinic and 100% attended booked follow-up appointments; the cost per clinic was £15 (£1.88 per patient, range 1.25–7.50). A median of 42 (range 15–56) patients per clinic attended the rural clinics and 70% of patients attended follow-up appointments; the cost per clinic was £34 (£0.81 per patient, range 0.61–2.23). Rural clinic attendance was higher than in the hospital clinic (p=0.007) and in the local clinic (p=0.004). Five years post-intervention, the attendance was 44 patients (range 25–85) per rural clinic and the cost per clinic was £34.

Conclusions: Rural epilepsy clinics were associated with higher attendance than the hospital or local clinic and the attendance rate remained higher 5 years post-intervention.

Keywords: Audit; clinic attendance; cost of care; epilepsy; follow-up; multi-disciplinary team; seizure; Uganda

Introduction

Epilepsy affects more people in low- and middle-income countries (LMIC) than in high-income countries (HIC) [1]. The prevalence of epilepsy across the whole population of Uganda has been reported to be four times higher than in the UK [1]. This is because of the higher incidence of infections, birth complications and trauma [2]. The epilepsy treatment gap defined by the proportion of people who have epilepsy but receive no treatment has been highlighted by the World Health Organization (WHO) [3]. In their systematic review, most low-income countries had a treatment gap of over 75% and Uganda was reported to have a significantly higher treatment gap than other LMIC [3], despite WHO in 1997 supporting global initiatives such as ‘Bringing Epilepsy Out of the Shadows’ [4]. In Uganda, the estimated incidence of epilepsy in the whole population is 215/100,000 [1]. Hence, in the

Kasese district, an estimated 1494 patients are affected [5]. Seventy-one per cent of the population in this area depends on subsistence farming as their only income and thus do not have disposable income to pay for medical care.

Interventions to reduce the epilepsy treatment gap have had limited and sometimes short-lived effects in African countries. In Ethiopia, a study to improve in-hospital epilepsy services reached only 20% of the population and 60% of those who attended defaulted after 2 years [6,7]. In Uganda, free epilepsy services are provided by the government and by some 'not-for-profit' hospitals such as Kagando Hospital which is owned and run by the Church of Uganda. However, the distance to travel to access these free services is often prohibitive [8]. Another barrier to epilepsy care is the low level of understanding of epilepsy and the associated stigma, the latter of which results in many children with seizures being hidden away to avoid embarrassment or social isolation [9]. As a consequence, epilepsy clinics across Africa are poorly attended and there is low uptake of even low-cost or free medication [10].

It was hypothesised that a treatment guideline and epilepsy clinics for children outside Kagondo Hospital, particularly in rural areas, would improve attendance. To determine if there were any long-term impacts of these interventions, attendance was re-audited at the clinics 6 months and 5 years after the intervention.

Methods

Over a 3-month period from March to May 2012, an audit was undertaken of initial and follow-up attendance at the free weekly epilepsy clinic at Kagando Hospital, south-west Uganda. The clinic had been in existence for 3 years and was advertised in the community by local churches, community outreach workers and charity workers. Interventions were then introduced in June 2012 and attendance at the hospital and newly established clinics (one

local and four rural) were audited for 3 months between January and March 2013. Attendance at clinics was then re-audited from January to March 2017. Data were collected prospectively for these periods which were selected to coincide with visits by UK paediatricians. Children were diagnosed with epilepsy if they had two or more unprovoked seizures at least 24 hours apart [11]. Patients were included in the analysis if they were diagnosed with epilepsy, whether or not they were commenced on medication.

The interventions included a guideline developed by a clinical officer (BG) at Kagando Hospital, a visiting paediatrician from the UK and a worker from a local charity for children with disabilities. The guideline included information on available medications (carbamazepine, phenobarbitone and phenytoin), when to commence treatment and how to identify any side-effects.

A further intervention included the establishment of an epilepsy clinic for children in an area local to the hospital but outside the hospital grounds (local clinic) as it had been reported that families did not attend hospital clinics owing to the fear of being charged. This clinic was run by the clinical officer who, after leaving secondary school, had received 3 years of clinical training on a government accredited Clinical Officer course. For 6 months, he worked alongside the visiting paediatrician who was supported by a UK-based charity (Accomplish Children's Trust) and then worked as the sole clinician. In addition, four epilepsy clinics in villages (rural clinics) were established and run by the same clinical officer. He ensured uniformity of care across the sites and also that there was a single point of contact for data collection. He was supported in both the local and rural clinics by local charity workers who educated those affected by epilepsy, their families and the surrounding community about the causes, treatment and long-term management. These clinics were funded by Accomplish Children's Trust. The rural clinics were held monthly in four locations in south-west Uganda and were advertised by local radio and word of mouth. A pharmacist

from Kagando Hospital attended the clinics to dispense medication. Consultations and medication dispensed at the rural clinics were free of charge. The clinics were held in a school, a government office and two small primary health clinics. It was intended that patients attending rural clinics were initially seen monthly whilst treatment was initiated until the medication dosage was stable, then once every two-to-three months. The provision of education by the local charity workers and application of the guideline meant that those on stable medication required little input from the clinical officer and hence they were able to concentrate on new or unstable patients.

The cost of the clinics was assessed in March 2013 and again 5 years later. This included transport for the epilepsy team and payment of the clinical officer and a local charity representative who coordinated outreach in the local and rural communities. The cost of the clinics per patient was calculated.

Statistical analysis

The data were tested for normality using the Shapiro–Wilk test and found to be non-normally distributed. Therefore, differences between groups were assessed for statistical significance using a Mann–Whitney U-test. Multiple comparisons were assessed using a Kruskal–Wallis H-test with Dunn's *post hoc* analysis and Bonferroni correction. Statistical tests were performed using SPSS version 24 (IBM, UK).

Results

Pre-intervention, one patient a month attended the hospital clinic and this was the same in the initial audit 6 months after the intervention and the hospital clinic was therefore closed. At the local clinic 6 months after intervention, a median of eight (range 2–12) patients attended per clinic with 100% attending follow-up. The cost of the local clinic was £15 median £1.88

(range 1.25–7.50) per patient. As a consequence of the greater attendance at the rural clinics (see below), the local clinic was withdrawn 1 year after the intervention and the patients transferred to the rural clinic closest to their home. At the rural clinics 6 months post intervention, there was a median of 42 (range 15–56) patients per clinic with a median 70% (range 50–95) of patients attending follow-up appointments. The cost of each rural clinic was £34, median £0.81 (range 0.61–2.23) per patient. Five years post intervention, attendance at the rural clinics was a median 44 patients (range 25–85) per clinic with a median of 96% (range 88–100) of patients attending follow-up. The cost per rural clinic remained £34, median 0.78 (range 0.40–1.17) per patient. Rural clinic attendance post intervention was higher than at the hospital clinic (p=0.007) and local clinic (p=0.004). Five years post intervention, rural clinics were cheaper per patient than the local clinic (p=0.018) had been during its 1-year existence. No data were collected on improvement in seizure frequency, but qualitative data suggested that the rural clinics may have improved the patients' quality of life. For example, some patients attending the rural epilepsy clinics repeatedly travelled for several days from neighbouring Democratic Republic of Congo, crossing major rivers and an international border.

Discussion

Attendance at rural epilepsy clinics was significantly greater than at the hospital and local clinic which was close to but outside the hospital. In addition, 5 years after their introduction, rural clinic attendance was sustained and the costs remained similar.

Despite free treatment, the hospital clinic was poorly attended compared with rural clinics, with only one patient a month accessing care. Other studies have reported similarly poor use of hospital-based epilepsy services in low-income countries. A study in Ethiopia on improving in-hospital epilepsy services by increasing staff and education and providing free

medication found that only 20% of those with epilepsy sought medical treatment [6]. In addition, up to 60% of those who did seek treatment defaulted after 2 years [7]. In contrast, this study found that the four satellite clinics reached 40% of the estimated population in Kasese with 96% attending follow-up.

Distance to travel has been highlighted as a concern in survey-based studies of epilepsy patients in India, Nigeria and Kenya [12]. In a Ugandan study, however, reducing the distance to health-care facilities did not result in greater use and it was shown that over a 3-year period, despite a higher proportion of the measured population living within 5 km of a health centre (72% of respondents versus 48% previously), the likelihood of not seeking medical care when ill was greater (OR 1.79, 95% CI 1.65–1.94) [5]. Whilst the rural clinics reduced the distance required to access epilepsy treatment for some, it is unlikely that this was the only factor which resulted in improved attendance and follow-up compared with the hospital and local clinic. A systematic review of epilepsy treatment in LMIC showed that the most likely reasons why epilepsy patients did not access treatment were cost, the availability of medication and superstition (40% of responders) [12]. In this study, the rural clinics provided free consultation and medication, but also included local charity workers who focused on providing education about epilepsy, both to those affected by epilepsy and their surrounding communities. This holistic approach has been used with positive results for other conditions to which a high level of stigma is attached such as HIV/AIDs [13,14]. Systematic reviews have demonstrated that attendance at the clinics and compliance with the free treatment available was improved in studies which also educated patients and communities about their condition [13,14]. Those systematic reviews included studies from both HIC and LMIC, suggesting that the approach may have global success [13,14].

This study has many strengths and some limitations. The intervention was developed in association with local care-givers and therefore was more likely to be acceptable. The

intervention's impact on attendance was assessed 6 months and 5 years later and the results were similar at both time points, suggesting that the intervention was effective in improving attendance for care and follow-up. A limitation of the study was that the children's seizure control was not assessed to determine whether the interventions had affected outcome. Nevertheless, the high proportion attending follow-up appointments and the distance some travelled to attend these appointments suggests that families thought that their children had benefited from attendance.

To conclude, the introduction of rural epilepsy clinics improved attendance and follow-up compared with hospital-based care and care in a local clinic and this improvement in attendance was sustained over 5 years.

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Competing interests: Dr Harris is a Trustee of Accomplish Children's Trust

Geolocation information: Uganda.

References

1 Fiest KM, Sauro KM, Wiebe S, et al. Prevalence and incidence of epilepsy. A systematic review and meta-analysis of international studies. Neurology. 2017;88:296–303.
2 World Health Organization. Epilepsy in the WHO African Region: Bridging the Gap. The Global Capaign Against Epilepsy: "Out of the Shadows. Geneva: WHO; 2004.
3 Meyer AC, Dua T, Ma J, et al. Global disparities in the epilepsy treatment gap: a systematic review. Bull WHO. 2010;88:260–266.
4 Kale R. Bringing epilepsy out of the shadows. BMJ. 1997;315:2–3.
5 Uganda Bureau of Statistics. National Population and Housing Census 2014 Area Specific Profiles: Kasese District. Retrieved from https://www.ubos.org/onlinefiles/uploads/ubos/2014CensusProfiles/KASESE.pdf, accessed on 31.10.2018
6 Berhanu S, Asmera J, Prevett M. Primary care treatment of epilepsy in rural Ethiopia. Ethiop Med J. 2002;16:235–240.
7 Berhanu S, Alemu S, Prevett M, et al. Primary care treatment of epilepsy in rural Ethiopia: causes of default from follow-up. Seizure. 2009;18:100–103.
8 Pariyo GW, Ekirapa-Kiracho E, Okui O, et al. Changes in utilization of health services among poor and rural residents in Uganda: are reforms benefitting the poor? Int J Equity Health. 2009;8:39.

9 de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. Epilepsy Behav. 2008;12:540–546.
10 Chin JH. Epilepsy treatment in sub-Saharan Africa: closing the gap. Afr Health Sci. 2012;12:186–192.
11 Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE official report: a practical clinical definition of epilepsy. Epilepsia. 2014;55:475–482.
12 Mbuba CK, Ngugi AK, Newton CR, et al. The epilepsy treatment gap in developing countries: a systematic review of the magnitude, causes, and intervention strategies. Epilepsia. 2008;49:1491–1503.
13 Mills EJ, Nachega JB, Bangsberg DR, et al. Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. PLoS Med. 2006;3:e438.
14 Hill S, Kavookjian J. Motivational interviewing as a behavioral intervention to increase HAART adherence in patients who are HIV-positive: a systematic review of the literature. AIDS Care. 2012;24:583–592.